Results from a Web-Based Family History Questionnaire for the Cohort of the Robert E. Mitchell Center for Prisoner of War Studies

Robert Hoyt MD FACP [1] Lawrence Williamson [2] Steven Linnville PhD [1]

[1] Robert E. Mitchell Center for Prisoner of War Studies, Navy Medicine Operational Training Center, Pensacola, Florida, [2] School of Psychological and Behavioral Sciences, University of West Florida, Pensacola, Florida

Abstract

Our previous report described how we designed an online family history questionnaire to collect computable data which can be used in clinical decision support for Vietnam-era repatriated prisoners of war medical history. This paper provides the summarized family history data. The top categories of diseases identified by 150 or more surveyed included high blood pressure, high cholesterol, diabetes, coronary artery disease, heart attacks, and cancer (unspecified).

Introduction

Capturing family history information is important as studies have shown most people are at moderate to strong risk of a medical condition with a genetic component.[1] Thus, data obtained from a detailed family history questionnaire may serve as a surrogate for personal genomic information to be included into paper or electronic health records.[2] However, obtaining such detailed family histories is time consuming, requires some expertise, [3] is not associated with clinician or patient reimbursement, and is dependent on the quality of information provided by the patient. As a result, many paper-based records, personal health records (PHRs) and electronic health records (EHRs) fail to record vital family history which can be used to screen at-risk individuals and their families. Furthermore, rarely is the information captured as structured data, amenable to computation. In spite of the increased adoption of electronic health records and personal health records, most commercial applications thus far do not include the ability to capture computable family history information. Data standards have been developed to help represent this important information, specifically, HL7 version 3 Clinical Statement Model and Clinical Genomics Family History Model, but significant limitations exist. [4]

In our previous report, our goal was to create such a secure online digital family history questionnaire (FHQ) that was computable and could be used to evaluate the hypotheses resilient individuals (defined as no psychiatric illnesses post-trauma) have a family history associated with fewer psychiatric and/or medical illnesses, compared to non-resilient individuals. This report instead will provide the descriptive summaries of the family medical histories of our cohort.

Report Documentation Page

Form Approved
OMB No. 0704-0188

1. REPORT DATE	2. REPORT TYPE	3. DATES COVERED
21 MAY 2014		**12-02-2013 to 21-05-2014**

4. TITLE AND SUBTITLE	5a. CONTRACT NUMBER
Results from a Web-Based Family History Questionnaire for the Cohort of the Robert E. Mitchell Center for Prisoner of War Studies	5b. GRANT NUMBER
	5c. PROGRAM ELEMENT NUMBER
6. AUTHOR(S)	5d. PROJECT NUMBER
Robert Hoyt; Lawrence Williamson; Steven Linnville	5e. TASK NUMBER
	5f. WORK UNIT NUMBER
7. PERFORMING ORGANIZATION NAME(S) AND ADDRESS(ES)	8. PERFORMING ORGANIZATION REPORT NUMBER
Robert E. Mitchell Center for Prisoner of War Studies,220 Hovey Road,Pensacola,FL,32508	**NMOTC-REMC-004**
9. SPONSORING/MONITORING AGENCY NAME(S) AND ADDRESS(ES)	10. SPONSOR/MONITOR'S ACRONYM(S)
Navy Medicine Operational Training Center, 220 Hovey Road, Pensacola, FL, 32508	**NMOTC**
	11. SPONSOR/MONITOR'S REPORT NUMBER(S)

12. DISTRIBUTION/AVAILABILITY STATEMENT
Approved for public release; distribution unlimited

13. SUPPLEMENTARY NOTES
Includes Tables

14. ABSTRACT
Our previous report, NMOTC-REMC-002, described how we designed an online family history questionnaire to collect computable data which can be used in clinical decision support for Vietnam-era repatriated prisoners of war medical history. This paper provides the summarized family history data. The top categories of diseases identified by 150 or more surveyed included high blood pressure, high cholesterol, diabetes, coronary artery disease, heart attacks, and cancer (unspecified).

15. SUBJECT TERMS
Electronic health records, information retrieval, questionnaires, genetics

16. SECURITY CLASSIFICATION OF:			17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON
a. REPORT	b. ABSTRACT	c. THIS PAGE			
unclassified	**unclassified**	**unclassified**	**Same as Report (SAR)**	**11**	

Methodology

Participants: Our study population was comprised of 430 male repatriated prisoners of war (RPWs) from the Vietnam War era, as well as 118 comparison group subjects, matched for gender, age, education and combat roles in Vietnam. These individuals visit the Robert E. Mitchell Center for Prisoner of War Studies, located in Pensacola, Florida on a near annual basis. The program has been in existence since 1973 with some RPWs having 39 years of longitudinal physical and psychological data.[5] In spite of severe malnutrition, torture and solitary confinement, a majority of RPWs did not develop any evidence of psychiatric disease during the 39 years of follow up. [6] This project was IRB approved; and, all patients signed a consent form.

Survey development: We used a commercial survey instrument (SurveyMonkey) to create the web-based survey.[7] A panel of experts were convened for survey development; a literature review was performed to identify existing FHQs; and recommendations made by the 2008 American Health Information Community's Family Health History Multi-Stakeholder Workgroup were included. [8] For additional details regarding the survey development, please see Hoyt et al [9]. The survey had the following sections.

1. Demographic-type questions to include gender, adopted status, twin status and ethnicity, to be answered by all participants prior to proceeding.
2. Personal health information divided into the following question categories. All categories have a free text optional answer option. The number of questions in each category is located in parentheses. In this section only participants will include the age of diagnosis in a drop down menu.
    a. General condition questions (8)
    b. Heart condition questions (5)
    c. Cancer questions (14)
    d. Brain disease/neurodegenerative disease questions (6)
    e. Mental disorder related to learning disability questions (2)
    f. Mental disorder other than related to learning disability questions (8)
    g. Substance abuse questions (2)
3. Mothers health
    a. Begins with living/deceased Y/N (drop down menu); current age or age of death (drop down menu), smoker status (drop down menu); served in military (drop down menu).
    b. The question categories 1-7 above are again asked (total of 50 questions) but there is no option to record age of diagnosis
    c. The survey questions are found in figure 2
4. Father's health and is identical to the mother's health section.
5. Sibling health and is identical to the mother's health section
6. Children's health and is identical to the mother's health section

We chose to develop our own FHQ to answer specific research questions but have enough flexibility for other studies. The current program does include psychological disorders but does not include nicotine or alcohol use. Furthermore, the categories for age of death ended at "60 years and older", which would not have been adequate to evaluate parental longevity. Lastly, as the program was written, each individual downloaded their own family health portrait to their

computer, making group data aggregation difficult. Our approach to create a customized FHQ was associated with numerous lessons learned, which are described in our previous report.

We elected to include information on first degree relatives only: proband/informant, children, siblings and parents in order to keep the FHQ concise and decrease the size of the resulting database. Also, the most common definition of a positive family history is the involvement of one or more first degree relatives.

Protected health information: A concerted effort was made to meet and exceed all of the expectations of research studies related to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, published by the Department of Health and Human Services. The method of delivery chosen was e-mail, a commonplace communication method and one adopted by a majority of the intended participants. The content of the message was an unassuming request for voluntary participation in an online survey. The message did not contain identifying information within the body of the message, and recipient email addresses were blind copied to reduce identification and the likelihood of unintended consequences in the improbable event that messages would be intercepted or sent in error. Included within the body of each message were two key elements for the survey; one, the Uniform Resource Locator (URL) used to gain access to the survey, and two, a unique identifier created for the sole purpose of this research. Lastly, the service used for hosting the web-based survey permitted anonymous data acquisition – allowing evaluators the ability to disable IP and email logging for survey participants.

The resulting data set was a de-identified collection of familial history results that were tied only to the unique identifier given to participants as part of the notification. The unique identifier served as a key, as allowed by the Privacy Rule for research purposes, for re-identifying the participants during data analysis after survey completion. The identifier was created and stored within a protected document used for re-identification purposes. This identifier was a randomly chosen eight digit number that was sequenced for each participant at both the first and fourth place values, representing the ones and thousands digits respectively, which was done in order to eliminate confusion in the event of typographical errors during time of survey submittal. It was possible that this level of obfuscation would not be necessary with a limited data set and data use agreements, but the methodology employed prevented participant identification in the unlikely event that the survey host experienced a security breach and subsequent data exposure.

Statistical Analysis: Four hundred forty-seven participants were contacted by e-mail for the survey. Ten participants preferred to take the survey using paper forms. Three hundred nineteen participants successfully completed the survey (paper and electronic) for a survey completion rate of 72 percent. The survey was open for approximately one year (March 2011 to June 2012) to allow for data collection and follow-up reminders. FHQ data was exported into SPSS version 19 for descriptive data analysis.[10]

Results

Table 1. summarizes the diseases reported by the patrons for their first degree family members and for themselves. These were derived from cross-tabulating the survey into disease type by family member (i.e., child, father, mother, sibling, and patron) and then total values were derived for each disease. The diseases reported are based on the knowledge and recollection of the patron's family medical history, and not documented medical diagnoses.

The most prominent diseases reported (affecting over 150 patrons and family members) included:

- High Blood Pressure
- Cancer (not specified)
- Cholesterol
- Arthritis
- Heart/Heart Attack
- Diabetes
- Coronary Artery Disease (CAD)

Diseases that were somewhat prominently reported (affecting at least 40 patrons and family members, but less than 150) included:

- Other Skin Cancer (not specified)
- Stroke
- Prostate Cancer
- Arrhythmia
- Dementia not caused by Alzheimer's Disease
- Asthma
- Lung Cancer
- Breast Cancer
- Kidney
- Melanoma

Diseases far less reported (affecting less than 39 down to 10 patrons and family members) included:

- Colon cancer
- Alzheimer's Disease
- Aneurism
- Peripheral Artery Disease (PAD)
- Lymphoma
- Cardiomyopathy
- Pancreatic Cancer
- Thyroid Cancer
- Brain (disease)
- Epilepsy
- Parkinson's Disease
- Ovarian Cancer
- Bladder Cancer

Finally, a variety of diseases (approximately 87) impacting less than 10 patrons and family members were reported and are listed in the table.

Table 2 includes common medical conditions with a genetic component recorded in the survey as listed by the participant and the participant's family and compared to national prevalence

statistics.[11–14] In general, the prevalence of diabetes and cardiovascular disorders with a genetic component was lower in our cohort. The prevalence of cancer, particularly lung cancer, was higher in our cohort, but that finding might have been due to our small sample size. The national prevalence rates for noncancer conditions included both men and women, while the prevalence rates of cancer conditions were for only elderly white males.

Conclusion

Family history is an important part of any medical record and is a potentially valuable tool for disease prediction, prevention and research. We are moving towards genetic information being part of all medical record systems, but obstacles remain such as cost, immature data standards and the fact that electronic health records are not ready for input of this data. Family history information should also be available in all electronic health records, in a computable format, so clinical decision support tools can remind clinicians of important testing and risk assessment. Unfortunately, there is not a simple generic family history questionnaire (FHQ) available for common use in primary care, for use with or without an EHR.

We developed a web based FHQ as part of a research study to help evaluate resiliency in repatriated prisoners of war. Included are lessons learned to create a concise FHQ for research purposes. Further work is needed to determine and validate the optimal family history core questions, the best methods to collect this information, how to integrate computable family history information into EHRs, interoperable data standards and future clinical support tools.

Disclaimer

The views expressed in this article are those of the authors and do not reflect the official policy or position of the Department of Defense, nor the US Government or the University of West Florida. This research was sponsored by the Office of Naval Research grant #FHP-FY08-01.

References

1. O'Neill SM, Rubinstein WS, Wang C et al. Familial risk for common diseases in primary care: the Family Healthware Impact Trial. Am J Prev Med 2009;Jun:36(6):506-14
2. Kmiecik T, Sanders D. Integration of Genetic and Familial Data into Electronic Medical Records and Healthcare Processes. February 2 2009. http://www.surgery.northwestern.edu/dos-contact/info-systems/Kmiecik%20Sanders%20Article.pdf Accessed January 10, 2011.
3. Suther S, Goodson P. Barriers to the provision of genetic services by primary care physicians: a systematic review of the literature. Genet Med 2003;5:70-6
4. Melton GB, Raman N, Chen ES et al. Evaluation of family history information within clinical documents and adequacy of HL7 clinical statement and clinical genomics family history models for its representation: a case report. J Am Med Inform Assoc. 2010;17:337-40
5. Robert E Mitchell Center for Prisoner of War Studies. http://www.med.navy.mil/sites/navmedmpte/nomi/rpow/Pages/default.aspx Accessed January 16, 2011.

6. Segovia F, Moore J, Linville S, Hoyt R, Hain R. Optimism Predicts Resilience in Repatriated Prisoners of War: A 37-Year Longitudinal Study. J Trauma Stress 2012;25:1-7
7. SurveyMonkey www.surveymonkey.com Accessed January 4, 2011.
8. Feero WG, Bigley MB, Brinner KM. New standards and enhanced utility for family history information in the electronic health record: an update from the American Health Information Community's Family Health History Multi-Stakeholder Workgroup. J Am Med Inform Assoc. 2008;15:723-8
9. Hoyt R, Linnville S, Chung HM, Hutfless B, Rice C. Digital family histories for data mining. Perspectives in Health Information Management. Fall 2013. http://perspectives.ahima.org/digital-family-histories-for-data-mining/#.UkmJwIZwqvY
10. Statistical Package for the Social Sciences (SPSS) http://www-01.ibm.com/software/analytics/spss/ Accessed June 3 2012
11. National Diabetes Information Clearinghouse. "National Diabetes Statistics, 2011." Available at http://www.diabetes.niddk.nih.gov/dm/pubs/statistics (accessed January 3, 2013).
12. National Cancer Institute. "Surveillance Epidemiology and End Results." Available at http://seer.cancer.gov/(accessed January 10, 2013).
13. Centers for Disease Control and Prevention. "Vital Signs: Prevalence, Treatment and Control of Hypertension—United States, 1999–2002 and 2005–2008." *Morbidity and Mortality Weekly Report (MMWR).* February 4, 2011. Available at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6004a4.htm (accessed August 13, 2013).
14. Centers for Disease Control and Prevention. "Summary Health Statistics for U.S. Adults: National Health Interview Survey, 2011." *Vital and Health Statistics* 10, no. 256 (December 2012). Available at http://www.cdc.gov/nchs/data/series/sr_10/sr10_256.pdf accessed August 13, 2013.

Table 1. Tabulated Diseases from REMC Family Survey

Condition	Child	Father	Mother	Sibling	Participant	Totals
High Blood Pressure	99	198	222	300	228	1047
Cancer	32	93	91	139	111	466
Cholesterol	38	49	46	132	183	448
Arthritis	19	44	107	84	146	400
Heart	6	114	41	64	26	251
Heart Attack	4	104	34	59	25	226
Diabetes	18	31	40	64	38	191
Coronary Artery Disease (CAD)	4	40	21	46	40	151
Other Skin Cancer	13	13	12	24	59	121
Stroke	2	34	61	14	7	118
Prostate Cancer	1	34	0	17	51	103
Arrhythmia	6	8	13	24	40	91
Dementia not caused by Alzheimer's Disease	0	18	41	9	3	71
Asthma	17	7	10	17	19	70
Lung Cancer	2	19	16	24	5	66
Breast Cancer	3	0	26	21	0	50
Kidney	2	12	6	15	14	49
Melanoma	5	4	3	10	19	41
Colon Cancer	2	10	13	12	2	39
Alzheimer's Disease	0	11	18	9	0	38
Aneurism	0	3	0	0	0	27
Peripheral Artery Disease (PAD)	0	3	5	4	11	23
Lymphoma	1	6	3	7	4	21
Cardiomyopathy	0	4	3	4	8	19
Pancreatic Cancer	0	6	1	9	3	19
Thyroid Cancer	3	1	4	5	4	17
Brain	1	1	7	7	0	16
Epilepsy	6	1	0	4	3	14
Parkinson	0	4	2	3	4	13
Ovarian Cancer	0	0	8	4	0	12
Bladder Cancer	0	5	0	4	2	11
Liver Cancer	0	6	3	0	0	9
Uterine Cancer	4	0	2	3	0	9
Congestive Heart Failure	0	5	2	1	0	8
Bypass	1	0	0	5	1	7
Tumor	1	0	2	3	1	7
Multiple Sclerosis (MS)	2	1	0	2	1	6
Throat Cancer	0	3	2	0	0	5

Transient Ischemic Attack (TIA)	0	1	2	0	2	5
Chromosome Condition	2	0	0	2	0	4
Squamous Cell Cancer	0	0	0	0	4	4
Testicular Cancer	2	0	0	1	1	4
Triple Bypass	1	0	0	3	0	4
Heart Valve	0	2	1	0	0	3
Unknown	0	0	2	0	1	3
Huntington's Disease	1	0	0	0	1	2
Aortic Stenosis	0	1	0	1	0	2
Asperger's Syndrome	2	0	0	0	0	2
Atrial Fibrillation	0	0	0	0	2	2
Back	0	0	0	1	1	2
Berry Aneurysm	0	0	1	1	0	2
Glioblastoma	1	0	0	1	0	2
Blood Clot	0	0	1	0	1	2
Carcinoma	1	0	0	0	1	2
Congestive Heart Disease	0	1	1	0	0	2
Graves' Disease	1	0	0	1	0	2
Mental Retardation	1	0	0	1	0	2
Mini Stroke	0	0	2	0	0	2
Mitro Valve Prolapse	0	0	0	0	2	2
Pace Maker	0	0	0	1	1	2
Stent	0	0	0	0	2	2
Stress	0	0	0	1	1	2
Cerebral Hemorrhage	0	0	1	0	0	1
Some Neurological Problems Traced to Vitamin B12 Deficiency	0	0	0	1	0	1
Abnormally slow nerve conduction rate	1	0	0	0	0	1
Adenocarcinoma	1	0	0	0	0	1
Aplastic Anemia	0	0	0	1	0	1
Arterial Occlusion in the Retina	0	0	0	0	1	1
Arteriosclerotic Heart Disease (ASHD)	0	0	1	0	0	1
Attention Deficit Disorder	1	0	0	0	0	1
Arteriovenous Malformation (AVM)	1	0	0	0	0	1
Brain Mets	0	0	0	1	0	1
Cancer of the Jaw	0	1	0	0	0	1
Colitis	1	0	0	0	0	1
Chronic Obstructive Pulmonary Disease (COPD)	0	0	1	0	0	1
Cornea Disease	0	0	0	0	1	1
Crohn's Disease	0	0	0	1	0	1

Degenerative Heart Disease	0	1	0	0	0	1
Dyslexia	0	0	0	1	0	1
Emphysema	0	2	1	0	0	3
Enlarged Heart	0	0	1	0	0	1
False Positive T Wave	0	0	0	0	1	1
Fibromyalgia	1	0	0	0	0	1
Genetic Heart Failure/ 7 Bypasses/ 6 Stents	0	0	0	0	1	1
Grand Mal Seizure	0	0	0	1	0	1
Hardening of the Liver	0	1	0	0	0	1
Heart Murmur	0	0	0	0	1	1
Heart Valve damage from Rheumatic fever (childhood)/ Hepatitis Induced Liver Cancer	0	1	0	0	0	1
Lymphangioleiomyomatosis (LAM) Disease	1	0	0	0	0	1
Loss of Pigmentation in Skin Covering Hand Area	1	0	0	0	0	1
Malignant Tumor in RLL removed	0	0	0	0	1	1
Membranous Glomerulonephritis	0	0	0	0	1	1
Microcephaly	1	0	0	0	0	1
Migraine Headaches	0	0	0	1	0	1
Morbid Obesity	0	0	0	1	0	1
Mesothelioma	0	0	0	1	0	1
Narcolepsy	0	0	0	1	0	1
Nasal Cancer	0	0	0	1	0	1
Nerve damage due to broken leg not fixed right	1	0	0	0	0	1
Non-Cancerous Brain Tumor Removed	0	0	0	1	0	1
Non-Hodgkin’s Lymphoma	0	0	0	1	0	1
Pericarditis	0	0	0	1	0	1
Primary Lateral Sclerosis (PLS)	0	0	0	0	1	1
Polio	0	1	0	0	0	1
Racing Heart	1	0	0	0	0	1
Renal Failure	0	0	0	1	0	1
Retina Collapse	0	0	0	1	0	1
Rheumatic Fever	0	1	0	0	0	1
Ruptured Aorta	0	0	0	0	1	1
Sarcoma	0	0	1	0	0	1
Serious Heart Condition	0	0	0	1	0	1
Sjogren's Disease	0	0	0	1	0	1
Sleep Apnea	1	0	0	0	0	1
Spleen Cancer	0	0	0	1	0	1

Tachycardia	0	0	0	0	1	1
Tracheal Cancer	0	1	0	0	0	1
Uterine (Endometrial) Cancer (Placental Trophoblastic Cancer)	1	0	0	0	0	1
Uterine or Ovarian Cancer-whichever is detected by pap smear	0	0	0	1	0	1

Table 2

Prevalence of Seven Medical Diseases with a Genetic Component, Compared to National Statistics

Condition	Participant	Mother	Father	Brother	Sister	National Statistics
Diabetes	11.6	12.5	9.7	8.9	8.2	26.9[a]
Myocardial infarction	8.1	10.6	32.6	11.7	3.9	18.3-24.7[b]
Stroke	2.1	19.1	10.6	1.8	2	6.5-10.5[c]
Hypertension	48.2	33	28.9	27.3	17.8	71.2[d]
Lung cancer	1.6	5	6	3.3	3.1	0.33-0.65[e]
Prostate cancer	12.8	NA	9.7	3.8	NA	4.8-10.8[f]
Colon or rectal cancer	0.63	4.1	3.4	2.1	1.1	0.85-1.7[g]

[a] Ages 65 and older, male and female, all ethnicities. American Diabetes Association. "Executive Summary: Standards of Medical Care in Diabetes—2010." *Diabetes Care* 33 (2010): S4–S10.

[b] Ages 65–74 and 75 and older, male and female, all ethnicities.. Centers for Disease Control and Prevention. "Vital Signs: Prevalence, Treatment and Control of Hypertension—United States, 1999–2002 and 2005–2008." *Morbidity and Mortality Weekly Report (MMWR).* February 4, 2011. Available at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6004a4.htm (accessed August 13, 2013).

[c] Ages 65–74 and 75 and older, male and female, all ethnicities. Centers for Disease Control and Prevention. "Vital Signs: Prevalence, Treatment and Control of Hypertension—United States, 1999–2002 and 2005–2008." *Morbidity and Mortality Weekly Report (MMWR).* February 4, 2011. Available at http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6004a4.htm (accessed August 13, 2013).

[d] Ages 65 and older , white, male and female, on treatment. National Cancer Institute. "Surveillance Epidemiology and End Results." Available at http://seer.cancer.gov/(accessed January 10, 2013).

[e] Ages 60–69 and 70–79, male, white. National Diabetes Information Clearinghouse. "National Diabetes Statistics, 2011." Available at http://www.diabetes.niddk.nih.gov/dm/pubs/statistics (accessed January 3, 2013).

[f] Ages 60–69 and 70–79, male, white. National Diabetes Information Clearinghouse. "National Diabetes Statistics, 2011." Available at http://www.diabetes.niddk.nih.gov/dm/pubs/statistics (accessed January 3, 2013).

[g] Ages 60–69 and 70–79, male, white.National Diabetes Information Clearinghouse. "National Diabetes Statistics, 2011." Available at http://www.diabetes.niddk.nih.gov/dm/pubs/statistics (accessed January 3, 2013).